Impact of ulcerative colitis on patients' lives: results of the Finnish extension of a global ulcerative colitis narrative survey

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Supplemental data for this article can be accessed here.

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ABSTRACT

Introduction: The Ulcerative Colitis (UC) Narrative is a global initiative to engage patients with UC, in order to help identify the impact of UC on patients' lives. The aim of the UC Narrative extension survey in Finland was to identify and describe the unmet needs in quality care.**Methods:** Seventeen Finnish physicians were surveyed in the original UC Narrative survey between 7 December 2017 and 24 January 2018. In the extension phase, Finnish UC patients, recruited through the Finnish patient association, were surveyed from 15 November to 3 December 2018, covering questions on disease characteristics, impact on life, most common challenges in communication with health care professionals (HCPs) and access to care.**Results:** Five hundred and eight patients with self-reported UC diagnosis participated (137 male [27.0%]). Diagnostic delay was, on average, 2.3 (SD 5.5) years; 14.4% had waited five years or more for diagnosis. Most patients (396; 78.0%) considered themselves to be in remission and rated their overall state of health as 'excellent' or 'good' (303; 59.7%). Most patients (79.6%) were satisfied with the communication with their HCPs, and the majority (74.2%) felt comfortable raising concerns and fears with HCPs. However, the satisfaction in discussing mental and emotional health impacts of UC was lower (44.3%). A relatively large number of patients (38.5%) felt that they would be a more successful person without UC.**Conclusions:** The UC Narrative survey highlighted the diagnostic delay in UC, challenges in communication with HCPs and the impact of UC on life from the patients' perspective.

Keywords: Ulcerative colitis ; inflammatory bowel disease ; quality of care ; diagnosis delay ; narrative

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Introduction

Ulcerative Colitis (UC) is an idiopathic, chronic inflammatory disorder of the colorectum causing diarrhea, rectal bleeding and abdominal pain [1]. Systemic features like fever, fatigue and weight loss are common especially in patients with moderate or severe colitis. Most commonly, UC follows a chronic intermittent course with periods of remission interspersed with relapse lasting for weeks or months. Especially in young adults, UC may cause serious ab-

dominal pain and disability [2]. Often patients with UC have reported a wide variety of symptoms long before the diagnosis.

Due to unpredictable recurrence periods and frequent fluctuations in the severity of physical symptoms, patients with UC have a significantly lower health-related QoL than the general population [3]. Time to diagnosis, access to care, and communication with HCPs, for example, are some of the areas with need for improvement. This is essential in order to meet the needs and expectations of the growing population of patients with Inflammatory Bowel Disease (IBD).

This present study is an extension of the UC Narrative survey, a global initiative created by Pfizer to engage patients with UC, in order to identify the impact of UC on patients' lives. The original survey was conducted by the global UC Narrative advisory panel comprised of patients with UC, as well as leading gastroenterologists, IBD nurses, a psychologist, and patient advocacy organizations from 10 countries. The aim of the survey was to identify the complex impact of UC on patients' personal and professional lives and to compare patients' and gastroenterologists' perceptions of UC burden and management approaches. The extension of the survey, including only patients, was available online through the Finnish patient association from 15 November 2018 to 3 December 2018.

Materials and methods

The original survey of Finnish physicians and patients was conducted online by The Harris Poll between 4 December 2017 and 9 February 2018. A total of 17 physicians (gastroenterologists or internists with a gastroenterology focus) participated. All participating physicians were required to see at least ten UC patients each month, with at least 10% of these patients currently taking a biologic. A total of 105 qualified complete responses from UC patients were achieved in the original Finland country fielding. The data from the original survey were kept separate from the extension phase survey and therefore the results presented in this report cover data only from the extension phase, carried out to gain a deeper insight on the lives of UC patients in Finland. The questionnaire sent to the participants can be found as a Supplementary file.

In the extension phase, fielded from 15 November to 3 December 2018 through the Finnish patient association via links posted on their website and social media, a total of 508 completes from UC patients were achieved. All included respondents had had an endoscopy to confirm diagnosis, none had had a colectomy, had ever taken medication for UC (those who had only ever taken a 5-ASA were excluded), and all had seen a gastroenterologist, internist or another provider at a gastroenterologist's/internist's office or clinic in the past 12 months.

Due to the nature of the survey, there was no formal statistical hypothesis or pre-determined sample size. Percentages were used for nominal variables; mean and SDs were used to describe quantitative variables. If data were not distributed normally, median and interquartile range (IQR) were used. Statistical analyses were primarily conducted in Quantum, the market research industry standard for data processing and tabulations, using the Student's *t*-test of proportions and means. Additional analyses (such as the IQR) were also conducted in SPSS as needed. The raw data were analyzed by The Harris Poll in both phases.

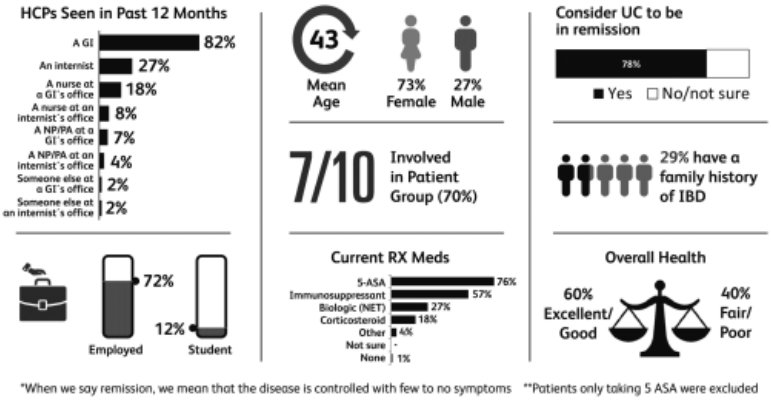
During the fielding of the original survey, the split between patients with a milder vs. moderate-to-severe disease was closely monitored and the group of patients with milder disease capped at 20% to ensure that the sample comprised mostly of moderate-to-severe patients (patients with 'moderate-to-severe' disease were defined as those who had ever taken a biologic or immunosuppressant, or had taken steroids for four or more months of the past 12 months. Patients with a 'milder' disease included all other patients; those who had only ever taken a 5-ASA were excluded). In the extension phase, in an effort to achieve the highest number of completes possible, no incoming responses from milder patients who otherwise qualified were terminated. The unweighted split between milder vs. moderate-to-severe patients ended up being 29% milder vs. 71% moderate-to-severe. The Harris Poll, therefore, applied a post-weight to the data to align the proportion of milder vs. moderate-to-severe patients with the 20/80 split in all other countries to keep the sample composition comparable.

Results

Demography

The respondents (n = 508) had a mean age of 43.2 (SD 13.69) years, 27% were men, and the median duration of UC since diagnosis was 8 years (IQR 3–14). All respondents resided in Finland. 78% of patients considered their UC to be in remission, and apart from UC, 12.3% were also diagnosed with depression, 9.2% with Irritable Bowel Syndrome, 7.7% with eczema, 7.5% with anxiety and 6.6% with diabetes. The respondent profile can be seen in Figure 1.

Figure 1. Respondent profile. HCP: Health Care Practitioner; GI: Gastroenterologist; NP: Nurse Practitioner; PA: Physician Assistant; UC: Ulcerative Colitis; RX: Prescription; 5-ASA: 5-aminosalicylic acid.



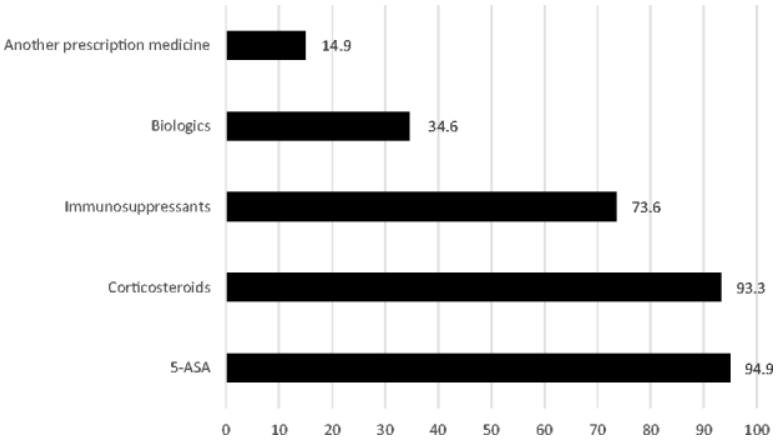
Access to care

Mean time between first experienced symptoms and diagnosis was 2.3 years (SD 5.5); less than one year by 57.7%, one year by 14.6%, two years by 8.1%, three years by 3.3%, four years by 2.0%, and five or more years by 14.4%.

Two thirds (66.1%) of the respondents had been treated at an IBD center during the last 12 months, and nearly three patients out of four (74.2%) reported having access to an IBD nurse at their gastroenterologist's office. Patients with access to an IBD nurse were more satisfied with the communication with their HCPs than those who did not have an IBD nurse available (81.7% vs. 73.5%). 54.5% were currently seeing a gastroenterologist to manage their UC, 41.7% an internist with gastroenterology focus, and 15.9% a primary care physician or general practitioner. In addition, 40.1% were currently seeing a nurse practitioner/physician's assistant in a gastroenterologist's office, 18.7% were seeing a nurse, 5.2% a nutritionist/dietician, 3.2% a psychiatrist, psychologist or therapist, 3.2% a rheumatologist, and 3.0% a gastroenterology surgeon. Nearly two-thirds of gastroenterologists (64.7%) wished there was a way for their patients to communicate with them more frequently while experiencing symptoms between visits. An online tool or smartphone app to better monitor and track patients' activities and symptoms was one of the top items physicians say would help to improve their patient relationships (58.8%).

The majority, 83.7% of patients, were satisfied with their current UC medications. However, many patients on biological therapy, 48.8%, wished that the medication could have been started earlier. 67.9% of all patients and 79.2% of patients not in remission wished that they had more options to treat their UC. The most common medications ever taken among the patients can be seen in Figure 2.

Figure 2. Ever taken medications (biologics: infliximab, adalimumab, golimumab, vedolizumab) (%, n = 508).



Symptoms

When asked about the amount of bathroom visits for any other reason than to urinate (e.g., to pass stool, air, blood, or mucus) on their best day, 2.0% reported less than one bathroom visit, 81.4% reported 1 to 3 bathroom visits, 14.2% reported four to nine bathroom visits, and 2.4% ten or more bathroom visits. Most patients (70.5%) reported having had at least one flare in the past 12 months; 28.5% one flare, 21.9% two flares, 11.4% three flares, 3.3% four flares, 2.7% five flares, 1.8% 6 to 9 flares, and 0.9% ten or more flares. The median number of flares was one for those who considered themselves in remission and two for those who did not.

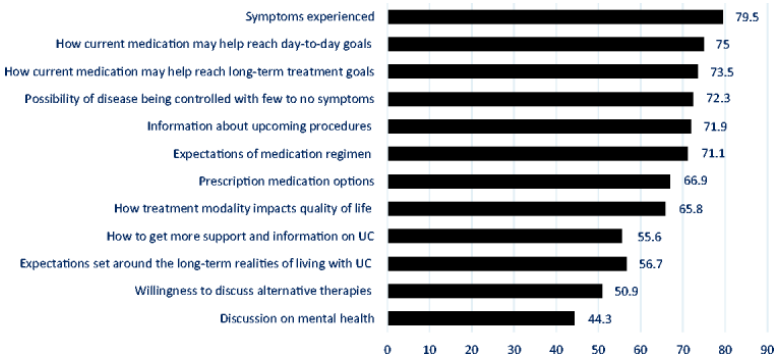
Patients do not always have sufficient knowledge regarding their disease. 68.4% of the respondents believed or were not sure that symptom control means the same as no active disease or inflammation. In addition, a quarter (24.4%) believed it to be false or were not sure that UC may be associated with conditions outside the colon.

Communication with HCPs

Most patients (79.6%) were satisfied with the communication with their HCPs, and the majority (74.2%) felt comfortable raising concerns and fears with HCPs.

The discussion aspects that patients were most satisfied with in the communication with their HCP are listed in Figure 3. The satisfaction in discussing mental/emotional health impacts of UC, however, was lower (44.3%). Importantly, 92.3% of the patients reported that they are honest with their gastroenterologist/internist when discussing their UC experiences, and 74.2% felt comfortable raising concerns and fears with their physician. However, 37.1% did not feel comfortable talking to their HCP about their sex life and personal relationship concerns, and 32.5% did not feel comfortable talking about their emotional concerns and fears, 63.5% wished they had more time at physician's appointments, and 44.3% felt their physician rarely had time to address all of their questions and concerns. 59.6% wished their physician spoke with them more about their goals for managing UC, and 53.3% wished their physician had discussed all available treatment options earlier so they had a better idea of their choices. 37.1% wished their physician talked more with them about their fears of medical treatments, and 31.6% often regretted not telling their physician more during their visit. 18.6% were hesitant about telling their physician if they did not take their medication as prescribed. Furthermore, 48.7% wished their physician better understood how much UC impacted their quality of life. 24.7% worried that if they asked too many questions, their physician would see them as difficult patients and it might affect the quality of their care.

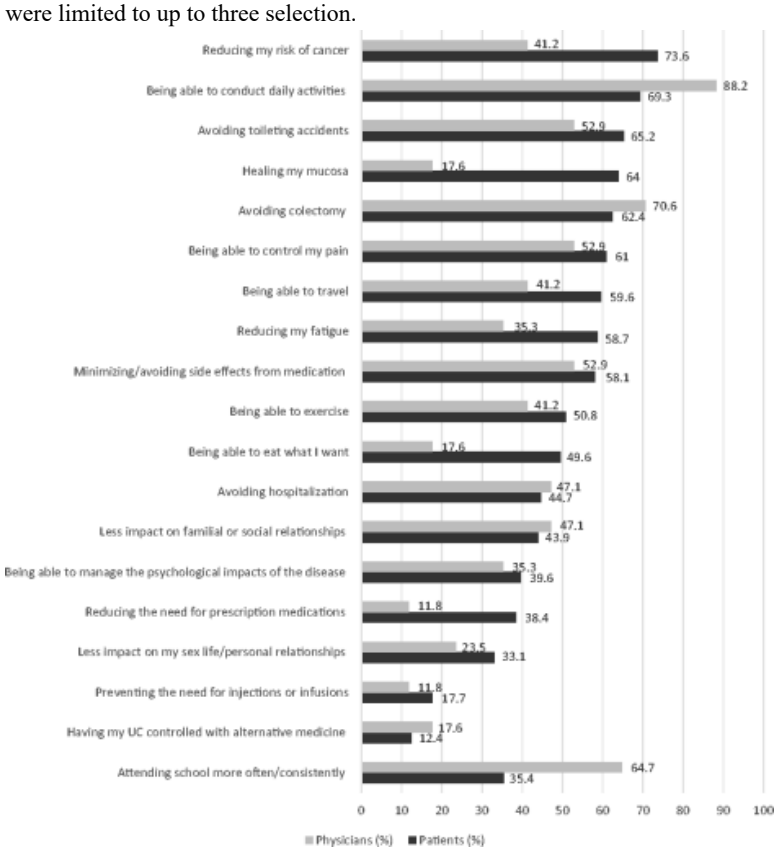
Figure 3. Patients' satisfaction in different communication aspects with their physicians (%, *n* = 508; NET of 'very satisfied' or 'somewhat satisfied').



Of all respondents, 42.9% reported not having set any goals for managing their UC with their physician, and 59.9% reported that if their treatment makes them feel good enough, they do not see a need to consider other treatment options even if they might make them feel better. Apart from shared treatment goals, physicians may not always recognize the needs of the patients. On a routine appointment, the topics patients mostly wanted to discuss were what to expect next from the UC treatment (47.6%), how to control inflammation (38.1%), and what to expect from UC in the long term (37.3%). Respondents could select up to three responses. The top priority for physicians, however, was symptoms since the last visit (71%).

The top priorities of patients and physicians in the management of UC, in general, can be seen in Figure 4.

Figure 4. Top priorities in UC management for patients and physicians (%, n = 508 [patients], n = 17 [physicians]). Respondents were limited to up to three selection.



Patients' worries and feelings

The majority of the patients (82.6%) considered UC mentally exhausting, and 73.3% worried about passing UC to their children or future children. 42.4% felt that UC controls their life rather than themselves. 37.4% of the respond-

ents often felt they spend more time in the bathroom than anywhere else. Patients worried most commonly about their risk of developing cancer (57.7%) and the potential worsening of their UC (54.6%). Respondents could select up to three responses. Physicians, however, believed most commonly that patients worry about needing a colectomy (94%). The most common worries of patients, as well as the estimates by physicians, can be seen in Figure 5.

Figure 5. Top worries of patients and the estimates of physicians (%, *n* = 508 [patients], *n* = 17 [physicians]). Respondents were limited to up to three selections.[AQ2]

During a flare, the respondents typically felt more fatigued (81.6%), hopeless (47.5%), isolated (35.1%), less confident (33.2%), scared (30.7%), guilty for missing events (30.3%), more angry in general (30.1%), embarrassed (26.3%), lonely (23.6%), restless (20.3%), and ashamed (18.0%).

On a more positive note, 88.8% of the respondents feel comfortable discussing their health issues with their family and friends. 87.2% felt that UC had made them more appreciative of the important things in life, and 69.5% felt that UC had made them more resilient.

Life with UC

A quarter (25.2%) of the patients had experienced that UC had impacted their family life (e.g. deciding not to have any/more children, postponing having children, deciding to adopt, stopping treatment to start a family, or postponing/ending/avoiding romantic relationships). Out of 366 employed patients, 80.5% considered their employer very understanding of their condition. On the other hand, 14.5% had not told their employer about their UC in fear of repercussions, and 34.9% did not feel comfortable discussing their health issues at the workplace. Many respondents felt that UC had affected their work in one way or another: 42.3% reported that UC had had a negative effect on their confidence at work, 31.6% reported being too tired due to UC to excel at the workplace, and 19.4% reported being in too much pain or distracted by the daily needs of UC to focus on work. Almost two out of five patients (38.5%) felt they would be a more successful person if they did not have UC. This was more true in younger adults (49.9% of respondents aged 18 to 34, 34.1% of respondents aged 35+), patients with moderate to severe disease (41.6% [26.5% of respondents with milder disease]) and those who were not in remission (60.4% [32.4% of respondents not in remission].

Out of all, 85.1% agreed that patient associations are important to the management of their UC; women, older patients and patients with access to an IBD nurse more often than others (women 87.3% vs. men 78.9%; patients older than 35 years 87.4% vs. patients up to 35 years 79.1%; patients with access to IBD nurse 87.1% vs. without access 79.1%). However, only 69.9% had ever interacted with a patient association in some way. 30.5% had ever participated in a support group online and 20.4% in a support group that meets in person, and 44.1% had ever relied on information from a patient association or organization or support group to help make choices about treatment and disease management. Interestingly, 40.6% had been referred to a patient association or organization by their physician and 29.1% had reached out to an organization.

Discussion

As in the present study, earlier studies have documented significant delays between first symptoms and diagnosis in IBD. [4–7]. In the Swiss IBD cohort study, the median diagnostic delay period in patients with UC was 4 months, which was shorter than that in patients with CD, who had the median delay of 9 months, and about 25% of patients the delay was more than two years [8]. Similar findings have been presented also in a recently published Austrian cohort, where the median diagnostic delay in UC was 3 months (1–10 months) [9]. In the Global UC Narrative survey, published so far only as an abstract, the mean delay between symptoms onset and UC diagnosis was 2.0 years; 42% of patients waited more than a year for diagnosis, and 11% of patients had waited five years or more [10]. These findings are in line with this extension phase study. Factors associated with diagnostic delay are not well understood and have been reported with conflicting results. However, ideal location, both a young and greater age at diagnosis, a high educational level (compared to middle degree level), active smoking, and socioeconomic factors were independently associated with longer diagnostic delay [9]. It is well recognized that diagnostic delay in Crohn's disease may lead to a reduced quality of life, due to symptoms caused by an untreated disease, as well as bowel damage with complications and an increased need for surgery. Therefore, a timely diagnosis is not important only for the patients but also for the HCPs due to the rising incidence of IBD and increased need for health care resources. Regardless, no study has reported the association between the clinical outcomes and diagnostic delays in patients with UC.

The present study showed that 42.9% of the respondents had not set any UC management goals with their physician. Furthermore, it was presented that physicians may not be fully clear on what are the patients' top worries and their goals for the management of the disease. The most desirable treatment goals for patients described in earlier studies have been symptom control and normalization of QoL. In this present survey, however, the patients' priorities in the management of their UC included reducing cancer risk, avoiding toileting accidents – in line with symptom control and normalization of QoL – and avoiding a colectomy. IBD patients are known to have more worries about their disease compared to patients with other chronic diseases. Most commonly described fears are the need for surgery and the possibility of having an ostomy bag, the fear of the side effects of medications, bowel incontinence, consequences of IBD on career and relationships, the risk of cancer, societal stigmatization and effects on fertility [11]. These findings are very much in line with the results of our survey. An open and honest discussion about the treatment goals is an important part of the shared-decision-making. Physicians have the duty of educating patients on the treatment options and recommending treatment to patients while taking into account patients' preferences, treatment goals, inclinations and risk profile. All of this may lead to an improved patient adherence and self-management, as well as increased patient satisfaction with HCPs. Communication is the backbone of chronic disease management.

It is important to identify the patients suffering from IBD-associated conditions and not to ignore them in order to improve the patient's QoL. Our survey showed that even in remission most patients suffer from IBD-related symptoms, including the need to visit the bathroom several times a day. However, the majority of respondents do not see a need to consider other treatment options even if those might make them feel better. Hence, understanding the different aspects of IBD enables patients to have realistic expectations, improves adherence and makes the new treatment options more acceptable.

Although 85.1% agreed that patient associations are important to the management of UC, only 69.9% had interacted with a patient association in any way. In many cases, patients are left to tend to themselves and find the resources alone; only 40.6% had been referred to a patient association by their physicians. These findings should encourage all HCPs to provide information on patient associations to their patients at an early stage.

Our study has several strengths and some limitations. This study provides important data on the diagnostic delay in UC, as well as an overview on UC patients' most common worries and fear. A major criticism is associated with the original survey sent to the HCPs. The number of respondents was low, which reflects the low number of HCPs taking part in IBD care in Finland. Additionally, the authors were not aware of the criterion on which the original questionnaire was sent out, because the vendor responsible for the execution of the survey classified this information confidential. Furthermore, voluntary participation creates a response bias; the results from the UC Narrative patient sample survey may not reflect the experiences of the broader UC population. Additionally, in the extension survey, 29% of patients had milder disease while 71% of patients had moderate-to-severe disease, so The Harris Poll applied a post-weight to the raw data to align the proportion of milder vs. moderate-to-severe patients with the 20/80 split in all other countries in the original UC Narrative.

Conclusion

The present survey demonstrated a considerable diagnostic delay in patients with UC and provided important information on unmet needs in quality care in Finland. Moreover, the UC Narrative survey has highlighted the challenges in communication with HCPs in Finland and the impact of UC on life from the patients' perspective.

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Disclosure statement

No potential conflict of interest was reported by the authors.[AQ1]

Author contributions

Statement of authorship: study design (UC Narrative Advisory Board, The Harris Poll), statistical analysis (The Harris Poll), initial manuscript drafting (SL, PM), critical revision and final approval (all authors).

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